Experiences from Implementation of PPI in Denmark 2009-2019

Mogens Hørder, University of Southern Denmark

- Setting the scene – Denmark – a profile
- When PPI first appeared on the stage-2009-2012
- Mapping of Implementation of PPI 2016-on
- Shared learning – a tool for implementation
- How to get the Researchers on board
- Where to go next?
POPULATION 5.6 mio
CIVIL SOCIETY is strong
VOLUNTARY Associations are plenty
HEALTHCARE is Public
RESEARCH has high ratings
Patient Involvement in Research

in a Project (bottom up)

Patient Involvement in Research

in a Strategy (top down)
National Forum for Health Research
Ministry of Health
Recommendations 2012 – top down

for the individual research project:

▪ Consider why and how PPI might be part of the design

for the roles of research funding bodies:

▪ Consider PPI as a requirement for funding

for the Implementation at the National Level:

▪ Exchange of experiences
▪ Train researchers and patients
"The Patient as Partner in Danish Health Research"

tasks of a national knowledge sharing project
by SDU and ViBIS 2016

- Mapping current PPI activities in Danish health research
- Sharing experiences about implementation of PPI
- Contributing to the training of researchers
- Establishing PPI networks in Denmark
Mapping of PPI in research 2018

- Aalborg Universitet (SUND)
- Region Nordjylland (Universitetshospital)
- Almen Medicin

- Aarhus Universitet (HEALTH)
- Region Midtjylland (alle hospitalsenheder)
- Almen Medicin

- SDU (SUND)
- Region Syddanmark (OUH, Sygehus Lillebælt, Sydvestjysk Sygehus, Sygehus Sønderjylland, Psykiatrien)
- Almen Medicin

- Københavns Universitet (SUND)
- Region Hovedstaden (Rigshospitalet)
- Almen Medicin

- Københavns Universitet (SUND) og SDU (SUND)
- Region Sjælland (Sjællands Universitetshospital, Psykiatrien)
Patient Involvement in Research in a Strategy

Visits at and interviews of Managements and Research Boards
Questions raised for a dialogue on PPI with research managers and research boards

- Has the research institution a strategy for PPI?
- Which roles do patients have in implementing PPI?
- Do you know about projects at the institution that uses PPI?
PPI in a research Strategy and patients in research Boards

Universities-Health: 0 out of 4
University Hospitals : 2 out of 6
Regional Hospitals : 3(5) out of 14

The Roles of Patients?

- Discussions on research strategy
- Prioritising research applications
- Dissemination of Research Strategy
A Booster for Implementation of PPI:

*Patient Centered Health Care* 2014 -on

Engaging Patients and the Public in:

*PRO*-Patient Reported Outcome

*Shared Decision Making*

*Patient and Public Involvement in Research* ?
Shared learning
Team building of researcher and patients in PPI
2014 - on

- 6 projects were accepted by a foundation
- The chairperson and a patient from each project shared plans for PPI – at a meeting 1 month from start
- The 6 projects shared experiences on successes and barriers in PPI - at a meeting 18-24 months from start
- After 4 years the projects were asked to evaluate their experiences from the processes of sharing

- The model now applied by more foundations and boards
Shared Learning
PhD students from the 4 DK Universities /Health
2017-2018-2019 : Training courses on PPI

Day 1 : Expectations & Goals-Introduction to PPI-Case A

Day 2 : Visiting faculty (UK) on Patient and Researcher Roles
Cases B and C
Open auditorium
Break – 3 weeks- preparing assignment

Day 3 : 2 groups of 10-12 students present cases on PPI
Individual plans for further PPI activity
Patient Involvement in Research in a Project (bottom up)

From 2014 contacts to and networking with more than 60 projects
## PPI at project level

60+ Projects identified

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<tr>
<th>Application of PPI</th>
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<tbody>
<tr>
<td>Cancer – long term side effects</td>
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<td>Neurodegenerative diseases</td>
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<td>Dementia</td>
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<td>Parkinson</td>
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<td>Chronic Heart Diseases</td>
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<td>Orthopedics</td>
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Questions raised by researchers

Which patients should be invited?

How should patients be introduced and trained?

Which types of research will benefit from PPI?

What are the roles of the researcher?
Is it worth doing?

“At the beginning of any research project, the researchers‘ don’t know what they don’t know’ until they involve patients/the public.”

Kristina Staley
Research Involvement Engagement (2015) 1:6
Supporting Partners in PPI

- Patient
- Researcher
- Managers
- Funders
- Guidelines
- Patient
- Organisations
- Editors
Road to success in PPI
Experiences 2009-2019

• Get started-do small things
• Support patients and researchers-shared learning
• Evaluate what works – and identify barriers
• Share experiences – join a network – also internationally
YES---- You can---
What is next?

PPI has become a topic of the national research policy

“User involvement in the research projects should be part of strategic research in Denmark”

(Benchmark no. 1. RESEARCH 2025, June 2017)
Learning from PPI implementation in DK

Top down AND Bottom up

The values and engagement of researchers and patients drives PPI from bottom up

Mind the PPI Gap

The understanding and engagement by the supporters drives PPI from top down
Learning from PPI Implementation in DK

Sharing-Partnership-Network

- Partnership in training
- Networking
- Shared learning
- Joint evaluation
- Quality teams

Primary drivers:
- Researchers
- Patients
Q &A